Progress on the Implementation of IC 16-38-4-7 (Birth Problems Registry)

as amended in First Regular Session

112th General Assembly (2001)

Reporting Period: July 2005-June 2006

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Indiana Birth Defects and Problems Registry (formerly called the Indiana Birth Problems Registry) is a population-based surveillance system that seeks to promote fetal, infant, and child health. The purpose of the Registry is to prevent birth defects and childhood developmental disabilities and to enhance the quality of life of affected Indiana residents. Birth defects are detected in three to five percent of all live births in the United States (rates of 300-500 per 10,000 births or 30-50 per 1,000 births), with lifetime costs estimated about $8 billion (from a 1995 California study based on 1992 dollars). They are the leading cause of infant mortality in the United States, and in Indiana account for more than 20 percent of all infant deaths. Some of these causes are entirely preventable, while others could be identified early and treated or managed in order to improve the quality of life of affected infants and their families. (See web site: www.in.gov/isdh/programs/ibdpr/index.htm.)

The 1986 Indiana General Assembly enacted a law (IC 16-4-10-6) to establish the Birth Problems Registry by January 1, 1987. In 2001, the Indiana Birth Problems Registry law (IC 16-38-4-7; 410 IAC 21-3) was amended to allow additional data sources to be used to improve the quality of the data. Data from the Indiana Birth Problems Registry will be used to detect trends in birth defects and suggest areas for further study; to identify epidemiological factors associated with birth defects; to address community concerns about the environmental effects on birth outcomes; to evaluate education, screening, and prevention programs; and to establish efficient referral systems that provide special services for the children with identified birth defects and their families.

In July 2004, statewide hospitals, physicians and health care providers were informed about the changes to the Indiana Birth Problems Registry (IC 16-38-4) made by PL 17-2004 during the 2004 legislative session. Hospital medical record directors/health information directors and physicians were provided a revised list of reportable conditions with the specifications and instructions to amend the monthly reporting process.

PL 17-2004 allowed the Indiana State Department of Health (ISDH) to increase the reporting age of children from two to three years of age, and added Pervasive Developmental Disorder and Fetal Alcohol Syndrome that is diagnosed in children less than 5 years of age to the reportable conditions list. Final rule with these amendments was published in Indiana Registry – May 2005. Indiana Birth Defects and Problems Registry (IBDPR) web site is updated according to the final rule.

Indiana State Department of Health staff obtained a three-year CDC Cooperative Agreement, a four-year Health Resource Service Administration (HRSA) Genetics Implementation Grant, a HRSA State Systems Development Initiative (SSDI), and HRSA's Title V Block Grant to fund the development of the enhanced IBDPR both programmatically and technically.

Case Ascertainment

The Indiana Birth Defects and Problems Registry (IBDPR) is considered a "passive" system because initial case ascertainment is through the electronic submission of hospital discharge data (HDD), with defined ICD 9 codes that identify birth defects and problems. However, in the early stages of program development, it was determined that up to 25% of the HDD were invalid. Therefore, the program protocol initially includes completing chart audits (which is indicative of an "active" birth defects registry) on the 44 CDC-targeted conditions to ensure the data submitted to CDC is as valid as possible and to ensure information sent to families is appropriate. Once two or three years of data are available, the need to continue chart auditing will be evaluated for each CDC-reported condition.

Hospital Reporting:

Since reporting started in July 2002, both the number of facilities reporting accurate data and the regularity of reporting has improved. By the end of August 2003, seventy-two (72%) facilities had reported their birth defects data. By May 2005, all 110 statewide facilities except one reported their 2003 and 2004 birth defects data. By the end of June 2006, all but 6 of the now 111 statewide reporting facilities had submitted their birth defects data based on hospital discharge data through March 2006. As of July 1, 2006, all but one hospital were uploading their monthly files using Indiana Health Data Center Portal. (This hospital continues to send data in a diskette via FedEx and is planning use the portal soon.)

The upgrades to the birth defects reporting system, which included an automatic reminder e-mail sent to the reporting hospitals, have improved regular reporting.

Physician Reporting:

The IBDPR uses physician reporting to identify children with birth defects that may not be diagnosable at birth and may, therefore, be diagnosed in a doctor's office rather than a hospital. The IBDPR staff considers a physician's submission as confirmation of a diagnosis. No chart auditing is done on charts in a physician's office. If IBDPR has received duplicate information from a hospital and no chart audit has been completed, the physician's report will be confirmation of that birth defect and no chart audit will be done at the hospital. IBDPR staff expects that reports of children with autism and fetal alcohol spectrum disorder will be ascertained primarily from physician reporting.

In January 2004 IBDPR staff sent a letter to primary care and specialty care physicians in the state who were likely to serve children under five. The letter which included a copy of the reporting form informed them of their legal obligation to report birth defects to the IBDPR if they are diagnosed in their office. Since then, a letter from the State Health Commissioner and a copy of the reporting form have been sent annually during February

(National Birth Defects Awareness month) reminding the practitioner of the law and the significance of reporting birth defects to the State. The physician's report form is available on the IBDPR web site (www.in.gov/isdh/programs/ibdpr/birth_defects.pdf).

During SFY 2006, Indiana Birth Defects and Problems Registry (IBDPR) received about 5 physician reports weekly. There are 3 physicians who report regularly. A total 552 submissions have been reported by 34 physicians.

Beginning in October 2006, genetics and newborn screening follow-up programs funded by ISDH will be required to submit reports to IBDPR of the clients seen by the grantee who meet the age criteria and are diagnosed with a birth defect..

Application Development

The IBDPR data mart continues to be developed and enhanced. In the spring of 2006, the Oracle database that stores birth defects data from physician reports was integrated into the Operational Data Store (ODS). Integrated data from physician reports increase the accuracy of child health profiles and the efficiency of medical record audits.

Also to download audit lists and increase the accuracy and efficiency of medical record audits, the Chart Audit Stand Alone (CASA) application was developed in early 2006. Through this Web-based application, chart auditors now can directly upload medical record audit data from their hospital to an Oracle database which is also integrated into ODS. No data entry is performed by in-house support staff.

In April 2006, a hospital began providing an authorized ISDH chart auditor with electronic access to their medical records. This saves money and time spent on traveling to the hospitals to conduct medical chart audit. As more and more hospitals switch to electronic medical records, it is anticipated that the IBDPR will be permitted access in other hospitals in the future.

Two permanent reports have been created. As required by the Centers for Disease Control and Prevention (CDC) Cooperative Agreement Grant from 2002-2005 to set up a birth defects data collection system separate from vital record information, IBDPR submitted the first set of annual data of the 2003 births (Tables 5 and 6) in April 2006, which will be published in Birth Defects Research Part A: Clinical and Molecular Teratology in December 2006. The second report is birth defects by county (Table 7) as required to report to the legislature.

Program Development

The goals of the program are to improve the quality of the data available on birth defects in Indiana and to provide information to physicians and families related to understanding the birth defect of their child and resources available to them. ISDH has promulgated rules regarding the case ascertainment (who and what needs to be reported to ISDH) with each legislative change.

An IBDPR Rule Amendment process was started in September 2005 which will require audiologists to report hearing loss as a reportable condition and includes the ICD 9 Codes for hearing loss as reportable codes. It is anticipated that this process will be completed in the late fall of 2006. A more efficient and user friendly physician reporting form will be introduced when the rule is approved.

In spring of 2006, IBDPR staff began sending information to families with infants born in 2003 with confirmed defects. Because so many of these packets were returned, it was determined that mailings would be sent to parents with 2004 births or later. The effectiveness of these mailings will be evaluated once the program is fully functioning.

National Meetings Attended

In January 2006, four staff members attended the 9th annual meeting of National Birth Defects Prevention Network (NBDPN), on "Advances and Opportunities for Birth Defects Surveillance, Research and Prevention" in Arlington, Virginia. Attendance to this conference was recommended by the Centers for Disease Control and Prevention (CDC) and was funded by HRSA Genetics Implementation Grant. The conference was designed to develop relationships with federal, state and professional organizations that are working towards common goals. It provided an opportunity to have discussions about the successful approaches to reduce and prevent birth defects.

IBDPR staff and ISDH Operational Data Store (ODS) staff participate in Connections: Community of Practice educational events (Web casts, site visits, and conference calls). Connections, launched in Fall 2004, assists state and local public health agencies to improve the health of children through the provision of accurate, timely, and comprehensive information and to strengthen the medical home. Connections is a program of the Public Health Informatics Institute and is supported by the Genetic Services Branch of the Health Resources and Services Administration's Maternal and Child Health Bureau (HRSA/MCHB). Indiana will be the site visit location for the November 2006 meeting.

The Region 4 Genetics Collaborative is a HRSA funded assembly that provides an opportunity for the seven states involved in the collaborative (Illinois, Indiana, Kentucky, Michigan, Minnesota, Ohio, and Wisconsin) to participate in a project to address inequities in genetics resources across the region. ISDH staff participate in monthly subcommittee teleconferences, one or two face to face subcommittee meetings annually, and an annual regional meeting.

Statute Requisites

1) The numbers and types of birth problems occurring in Indiana by county:
The data presented in Tables 1- 3 were obtained by the data files submitted to IBDPR by statewide hospitals as required by Birth Problems Registry law (IC 16-38-4-7; 410 IAC 21-3). The hospitals extract these data from their hospital discharge (UB-92) records.

IBDPR started collecting birth defects data separate from vital records data in the fall of 2002. Therefore, we have analyzed these data beginning with the children born in 2003 according to the conditions or categories listed in IBDPR's Reportable Conditions List (Table 1). ISDH Vital Records data reported 86,462 live births for 2003.

To verify the accuracy of hospital discharge data, IBDPR targeted 44 specific birth defects of the reported conditions to be audited by ISDH staff/contractors. These 44 defects are recommended by National Birth Defects Prevention Network and are published for most of the states nationwide in Birth Defects Research Part A: Clinical and Molecular Teratology, annually. ISDH chart auditors visit the hospitals and review the medical records of the children that have been reported to IBDPR with one or more targeted conditions to confirm the conditions or to determine them as probable (Table 4). About 77% of the children reported as having birth defects through hospital discharge data were determined to have confirmed conditions based on Medical chart audits for 2003 births. Of the targeted birth defects reported and confirmed, about 80% are to non-Hispanic white children, 10% to non-Hispanic black children, 6% to Hispanic children, <1% to Asian children and American Indian, and 3% to children of other races/ethnicities.

The following explains the attached tables:

Table 1 shows the number of children reported by the hospitals through discharge ICD 9 codes for each reportable condition category. These are unduplicated children for each condition category. However, many children with birth defects or problems have more than one defect, so one child may be reflected in more than one condition category. These numbers do not reflect confirmation of the defect, merely hospital reporting.

Table 2 shows the number of children reported with only one reportable condition and Table 3 shows the number of children reported with more than one reportable condition and the count is unduplicated by condition category. These tables are subsets of Table 1 and, again, do not reflect whether there is a confirmed diagnosis that supports the discharge code. More children are reported with more than one condition or anomaly.

Table 4 reflects the targeted conditions by categories reported to the IBDPR by hospital discharge date for children born in 2003, where the medical chart audit found the condition to be confirmed or probable by chart audit. The percentage of confirmed vs. reported conditions reflects the validity of the hospital discharge reporting.

In Table 4, for the first year the birth defects found in the "Ear, Face, and Neck" category were identified accurately. "Chromosomes and Syndromes" were also very well documented. Reports through hospital discharge data of "Fetal Alcohol Syndrome" were only able to be substantiated by chart audit in 34% of the children. Once we have 2-3 years of data to review, staff will be able to identify the specific conditions that are accurately reported through hospital discharge. Many times the ICD-9 codes listed on the hospital discharges are conditions that are possible but could be ruled out with further testing.

Table 5 provides the counts and rates per 10,000 births by race of confirmed and probable targeted birth defect conditions for Indiana children born in 2003 who have been reported to IBDPR. (A "probable" condition is one that has been audited where the criteria for confirmation was not complete but was adequate enough to determine the condition to be likely. A "probable" condition is counted as confirmed for counts and rates.) Overall rate of 309 per 10,000 births is within national estimates.

Table 6 indicates Trisomy (the presence of three, rather than the normal two, copies of a chromosome, e.g., children born with a third copy of their chromosome 21 have Down Syndrome) counts and rates of infants born in 2003 by maternal age.

Table 7 shows the counts and rates per 1,000 births of confirmed and probable targeted birth defect conditions for Indiana children born in 2003 for each county of Indiana. If the count is less than 5, it is indicated as "less than reportable numbers."

2) <u>The amount of use of the birth problems registry by researchers:</u>
Annual Indiana data of the 2003 births (Table 5) were submitted to National Birth Defects Prevention Network (NBDPN) in April 2006 which will be published in Birth Defects Research Part A: Clinical and Molecular Teratology in December 2006. IBDPR did not receive any other data requests from researches within this fiscal year. The data will be most useful for research and analysis when several years of data are available.

3) <u>Proposals for the prevention of birth problems occurring in Indiana:</u>
The Folic Acid Campaign marketing activities continued with funding from Title V through May 2006. The purpose of the Campaign is to increase awareness and stimulate behavior change with the target audience (women of child bearing age) through educating and marketing a new theme, "Take It, Seriously." Distribution of materials will continue. Activities for FY 2006 include:

- The report on the evaluative phone surveys with consumers and physicians/teachers was completed.
- Distributed Folic Acid Friendly Office Kits (1st quarter 2005) to all WIC Clinics (approximately 160) statewide.
- Provided displays and educational presentations to bridal trade shows and educational conferences.
- Designed middle and high school educational curriculum, now available on the Web site.
- The "Take It, Seriously" message was marketed in college newspapers, at local sports events, on the radio, and on bookmarks distributed to libraries.
- A follow-up consumer phone survey was completed to determine any increase in folic acid awareness and/or a change in behavior that has occurred in the last year. Of those surveyed in 2006, everyone knew something about folic acid (a 25% improvement). All knowledge levels increased, but there was only a 1% increase in those who said they knew a lot about folic acid. However, when asked about when folic acid should be taken, 55% (up from 10%) indicated that it should be take before pregnancy. This is a good outcome.

- Web site is being maintained and up-dated: (www.in.gov/isdh/programs/FolicAcid)

The Fetal Alcohol Spectrum Disorder (FASD) Task Force met regularly throughout the year to facilitate the development of the needs assessment and strategic plan. The goal of this effort is that "No baby shall be born in Indiana with Fetal Alcohol Spectrum Disorder." The following activities were completed in the last year:

- The needs assessment and strategic plan for addressing Fetal Alcohol Spectrum Disorders (FASD) was completed in June 2006. The strategic plan will be finalized and put on the Web site in the near future.
- The goals of a prevention campaign were determined to be:
    1. To increase awareness of the consequences of alcohol consumption by pregnant women through a direct marketing campaign throughout the state.
    2. To educate Indiana communities about FASD and how to prevent it.
    3. To support the efforts of up to four local communities to plan and implement the FASD Prevention Campaign.
    4. To replicate FASD Prevention Campaigns in additional communities.
    5. To evaluate the FASD Prevention Campaign throughout the state.
- As part of the needs assessment and strategic plan development, surveys were developed, distributed and compiled for women and health professionals, and community dialogues were held to gain insights about the plan.
- Funding opportunities to implement the plan are being evaluated.

Appendix

Table 1: Hospital Discharge Data reported to IBDPR of Children with Reportable Conditions by Birth Year

Name/Category	ICD-9-CM Codes	2003	2004	2005
Cardiovascular	745.00-747.99	1897	2172	2222
Central Nervous System	740.00-742.99	364	315	304
Chromosome and Syndromes	758.00-758.99	194	202	194
Cleft Palate and Cleft Lip	749.00-749.99	159	190	164
Congenital Anomalies-Other and Unspecified	759.00-759.99	200	159	168
Ear, Face and Neck	744.00-744.99	200	201	191
Eye	743.00-743.99	253	208	141
Fetal alcohol syndrome	760.71	16	17	13
Gastrointestinal	750.30-751.99	370	491	490
Genitourinary	752.00-753.99	1349	1474	1274
Integument	757.00-757.99	402	816	1243
Musculoskeletal	754.00-756.99	1675	1766	1644
Respiratory	748.00-748.99	310	346	333
Upper Alimentary Tract	750.00-750.29	374	355	302
Adenoma of lung or bronchus	212.30		2	1
Anomalies of jaw	524.00-524.10	54	55	62
Anterior horn cell disease	335.00-335.99	4	8	1
Aplastic anemia-Constitutional	284.00	1		1
Autism, Childhood disintegrative disorder, Aspergers, Rett syndrome, and Pervasive developmental disorders not otherwise specified	299.00-299.99	44	5	1
Cerebral degenerations usually manifest in childhood	330.00-330.99	8	3	3
Coagulation defects	286.00-286.50	27	20	9
Congenital nystagmus	379.51	5	2	7
Diabetes mellitus	250.00-250.99	165	112	49
Dyshormonogenic goiter	246.10	3		
Glaucoma of childhood	365.14			
Hemolytic anemias-Hereditary	282.00-282.99	123	151	118
Immune mechanism disorders	279.00-279.99	51	38	14
Mesothelioma of peritoneum	211.80		1	
Mesothelioma of pleura	212.40			
Muscular dystrophies and myopathies	359.00-359.99	13	14	7
Myelofibrosis-Acute	289.80			
Neoplasms-Benign skin	216.00-216.99	141	116	96

Name/Category	ICD-9-CM Codes	2003	2004	2005
Neoplasms (Digestive organs to unspecified)	230.00-239.99	63	40	32
Neoplasms (Malignant lip to leukemia unspecified)	140.00-208.99	86	73	35
Paraproteinemias-Other	273.20			
Polycythemia-Familial	289.60			
Retinal dystrophies-Hereditary	362.70			
Retrolental fibroplasia	362.21	197	181	175
Strabismus and other disorders of binocullar eye movement	378.00-378.99	84	65	30
Testicular dysfunction-Other	257.80		1	
Thrombocytopenia-Primary	287.30	36	35	12
Waldenstrom's macroglobulinemia	273.30		1	1
White blood cell diseases	288.00-288.99	639	581	331

Table 2: Hospital Discharge Data reported to IBDPR of Children with only One Reportable Condition by Birth Year

Name/Category	ICD-9-CM Codes	2003	2004	2005
Cardiovascular	745.00-747.99	361	437	479
Central Nervous System	740.00-742.99	41	45	65
Chromosome and Syndromes	758.00-758.99	16	24	31
Cleft Palate and Cleft Lip	749.00-749.99	47	37	49
Congenital Anomalies-Other and Unspecified	759.00-759.99	28	13	30
Ear, Face and Neck	744.00-744.99	82	82	91
Eye	743.00-743.99	73	72	52
Fetal alcohol syndrome	760.71	3	4	5
Gastrointestinal	750.30-751.99	93	140	124
Genitourinary	752.30-753.99	581	621	652
Integument	757.00-757.99	285	605	978
Musculoskeletal	754.00-756.99	642	653	653
Respiratory	748.00-748.99	63	69	60
Upper Alimentary Tract	750.00-750.29	205	211	189
Adenoma of lung or bronchus	212.30		1	
Anomalies of jaw	524.00-254.10	4	6	5
Anterior horn cell disease	335.00-335.99		1	
Aplastic anemia-Constitutional	284.00			
Autism, Childhood disintegrative disorder, Aspergers, Rett syndrome, and Pervasive developmental disorders not otherwise specified	299.00-299.99	7	1	1
Cerebral degenerations usually manifest childhood	330.00-330.99	2		
Coagulation defects	286.00-286.50		9	1
Congenital nystagmus	379.51	1		3
Diabetes mellitus	250.00-250.99	52	44	31
Dyshormonogenic goiter	246.10	1		
Glaucoma of childhood				
Hemolytic anemias-Hereditary	282.00-282.99	38	43	45
Immune mechanism Disorders	279.00-279.99	5	5	
Mesothelioma of peritonium	211.80			
Mesothelioma of pleura	212.40			
Muscular dystrophies and myopathies	359.00-359.99	4		
Myelofibrosis-Acute	289.80			
Neoplasms-Benign skin	216.00-216.99	75	72	60
Neoplasms (Digestive organs to unspecified)	230.00-239.99	16	11	7
Neoplasms (Malignant lip to leukemia unspecified)	140.00-208.99	18	17	12
Paraproteinemias-Other	273.20			
Polycythemia-Familial	289.60			

Name/Category	ICD-9-CM Codes	2003	2004	2005
Retinal dystrophies-Hereditary	362.70			
Retrolental fibroplasia	362.21	25	21	19
Strabismus and other disorders of binocular eye movement	378.00-378.99	12	7	
Testicular dysfunction-Other	257.80		1	
Thrombocytopenia-Primary	287.30	3	7	3
Waldenstroms macroglobulinemia	273.30			1
White blood cell diseases	288.00-288.99	334	261	172
Total number of children with only one Reportable Condition		3117	3520	3818

Table 3: Hospital Discharge Data Reported To IBDPR Of Children with More Than One Reportable Condition and Unduplicated by Category by Birth Year

Name/Category	ICD-9-CM Codes	2003	2004	2005
Cardiovascular	745.00-747.99	1536	1735	1743
Central Nervous System	740.00-742.99	323	270	239
Chromosome and Syndromes	758.00-758.99	178	178	163
Cleft Palate and Cleft Lip	749.00-749.99	112	153	115
Congenital Anomalies-Other and Unspecified	759.00-759.99	172	146	138
Ear, Face and Neck	744.00-744.99	118	119	100
Eye	743.00-743.99	180	136	89
Fetal alcohol syndrome	760.71	13	13	8
Gastrointestinal	750.30-751.99	277	351	366
Genitourinary	752.30-753.99	768	853	622
Integument	757.00-757.99	117	211	265
Musculoskeletal	754.00-756.99	1033	1113	991
Respiratory	748.00-748.99	247	277	273
Upper Alimentary Tract	750.00-750.29	169	144	113
Adenoma of lung or bronchus	212.30		1	1
Anomalies of jaw	524.00-254.10	50	49	57
Anterior horn cell disease	335.00-335.99	4	7	1
Aplastic anemia-Constitutional	284.00	1		1
Autism, Childhood disintegrative disorder, Aspergers, Rett syndrome, and Pervasive developmental disorders not otherwise specified	299.00-299.99	37	4	
Cerebral degenerations usually manifest childhood	330.00-330.99	6	3	3
Coagulation defects	286.00-286.50	27	11	8
Congenital nystagmus	379.51	4	2	4
Diabetes mellitus	250.00-250.99	113	68	18
Dyshormonogenic goiter	246.10	2		
Glaucoma of childhood				
Hemolytic anemias-Hereditary	282.00-282.99	85	108	73
Immune mechanism Disorders	279.00-279.99	46	33	14
Mesothelioma of peritonium	211.80		1	
Mesothelioma of pleura	212.40			
Muscular dystrophies and myopathies	359.00-359.99	9	14	7
Myelofibrosis-Acute	289.80			
Neoplasms-Benign skin	216.00-216.99	66	44	36
Neoplasms (Digestive organs to unspecified)	230.00-239.99	47	29	25
Neoplasms (Malignant lip to leukemia unspecified)	140.00-208.99	68	56	23
Paraproteinemias-Other	273.20			
Polycythemia-Familial	289.60			

Name/Category	ICD-9-CM Codes	2003	2004	2005
Retinal dystrophies-Hereditary	362.70			
Retrolental fibroplasia	362.21	172	160	156
Strabismus and other disorders of binocular eye movement	378.00-378.99	72	58	30
Testicular dysfunction-Other	257.80			
Thrombocytopenia-Primary	287.30	33	28	9
Waldenstroms macroglobulinemia	273.30		1	
White blood cell diseases	288.00-288.99	305	320	159

Table 4: Targeted Conditions Reported To IBDPR Via Hospital Discharge Data For Children Born In 2003 Where Medical Chart Audit Found The Condition To Be Confirmed Or Probable

Category	ICD-9-CM Codes	Targeted	Confirmed/ Probable	Confirmed/Probable Percentage
Cardiovascular	745.00-747.99	4902	3592	73.3
Central Nervous System	740.00-742.99	655	483	73.7
Chromosome and Syndromes	758.00-758.99	744	713	95.8
Cleft Palate and Cleft Lip	749.00-749.99	466	392	84.1
Ear, Face and Neck	744.00-744.99	7	7	100
Eye	743.00-743.99	32	24	75
Fetal alcohol syndrome	760.71	24	9	37.5
Gastrointestinal	750.30-751.99	616	564	91.6
Genitourinary	752.00-753.99	970	804	82.9
Musculoskeletal	754.00-756.99	351	211	60.1
Respiratory	748.00-748.99	30	27	90

Table 5: Indiana Confirmed and Probable Counts and Rates by Race of the Targeted Conditions for 2003 Births (rates displayed in the shaded area).

Indiana

Birth Defects Counts and Rates 2003 - 2003

(Rates per 10,000 live births.)

	Race/Ethnicity						
Defect	Non-Hispanic White	Non-Hispanic Black	Hispanic	Asian or Pacific Islander	American Indian or Alaskan Native	Other / Unknown	Total
Anencephalus	3	1	2	0	0	0	6
	0.44	1.08	2.96	0	0		0.69
Aniridia	0	1	0	0	0	0	1
	0	1.08	0	0	0		0.12
Anophthalmia/microphthalmia	3	0	1	0	0	1	5
	0.44	0	1.48	0	0		0.58
Anotia/microtia	1	0	2	0	0	0	3
	0.15	0	2.96	0	0		0.35
Aortic valve stenosis	21	1	0	0	0	0	22
	3.05	1.08	0	0	0		2.54
Atrial septal defect	438	66	23	1	0	9	537
	63.70	71.37	34.01	22.73	0		62.11
Biliary atresia	6	0	1	0	0	1	8
	0.87	0	1.48	0	0		0.93
Bladder exstrophy	0	0	0	1	0	1	2
	0	0	0	22.73	0		0.23
Choanal atresia	10	2	1	0	0	0	13
	1.45	2.16	1.48	0	0		1.50
Cleft lip with and without cleft palate	86	5	8	0	0	5	104
	12.51	5.41	11.83	0	0		12.03
Cleft palate without cleft lip	37	5	2	0	0	2	46
	5.38	5.41	2.96	0	0		5.32
Coarctation of aorta	41	7	3	1	0	1	53
	5.96	7.57	4.44	22.73	0		6.13
Common truncus	5	2	0	0	0	0	7
	0.73	2.16	0	0	0		0.81
Congenital cataract	6	2	2	0	0	0	10
	0.87	2.16	2.96	0	0		1.16
Congenital hip dislocation	39	1	4	0	0	2	46
	5.67	1.08	5.91	0	0		5.32
Diaphragmatic hernia	21	2	2	0	0	0	25
	3.05	2.16	2.96	0	0		2.89
Down syndrome	71	7	2	1	0	4	85
	10.33	7.57	2.96	22.73	0		9.83
Ebstein's anomaly	3	1	0	0	0	0	4
	0.44	1.08	0	0	0		0.46
Encephalocele	4	1	1	0	0	0	6
	0.58	1.08	1.48	0	0		0.69
Endocardial cushion defect	43	3	2	0	0	1	49
	6.25	3.24	2.96	0	0		5.67
Esophageal atresia/tracheoesophageal fistula	13	1	1	1	0	1	17
	1.89	1.08	1.48	22.73	0		1.97

Indiana

Birth Defects Counts and Rates 2003 - 2003

(Rates per 10,000 live births.)

Defect	Race/Ethnicity						
	Non-Hispanic White	Non-Hispanic Black	Hispanic	Asian or Pacific Islander	American Indian or Alaskan Native	Other / Unknown	Total
Fetus or newborn affected by maternal alcohol use	0	3	0	0	0	1	4
	0	3.24	0	0	0		0.46
Gastroschisis	17	0	2	0	0	0	19
	2.47	0	2.96	0	0		2.20
Hirshsprung's disease (congenital megacolon)	6	1	0	1	0	0	8
	0.87	1.08	0	22.73	0		0.93
Hydrocephalus without Spina Bifida	42	9	3	0	0	3	57
	6.11	9.73	4.44	0	0		6.59
Hypoplastic left heart syndrome	13	2	0	1	0	2	18
	1.89	2.16	0	22.73	0		2.08
Hypospadias and Epispadias	166	30	6	0	0	9	211
	24.14	32.44	8.87	0	0		24.40
Microcephalus	51	8	5	0	0	2	66
	7.42	8.65	7.39	0	0		7.63
Obstructive genitourinary defect	145	15	7	0	1	5	173
	21.09	16.22	10.35	0	103.09		20.01
Omphalocele	6	0	0	0	0	0	6
	0.87	0	0	0	0		0.69
Patent ductus arteriosus	219	38	15	2	0	8	282
	31.85	41.09	22.18	45.45	0		32.62
Pulmonary valve atresia and stenosis	67	8	2	2	0	5	84
	9.74	8.65	2.96	45.45	0		9.72
Pyloric stenosis	144	11	10	0	0	1	166
	20.94	11.90	14.79	0	0		19.20
Rectal and large intestinal atresia/stenosis	15	1	0	0	0	1	17
	2.18	1.08	0	0	0		1.97
Reduction deformity, lower limbs	6	1	0	0	0	2	9
	0.87	1.08	0	0	0		1.04
Reduction deformity, upper limbs	17	0	3	0	0	1	21
	2.47	0	4.44	0	0		2.43
Renal agenesis/hypoplasia	16	1	3	1	0	1	22
	2.33	1.08	4.44	22.73	0		2.54
Spina bifida without anencephalus	36	2	9	0	0	2	49
	5.24	2.16	13.31	0	0		5.67
Tetralogy of fallot	25	4	0	0	0	2	31
	3.64	4.33	0	0	0		3.59
Transposition of great arteries	28	3	3	1	0	1	36
	4.07	3.24	4.44	22.73	0		4.16
Tricuspid valve atresia and stenosis	6	0	0	0	0	1	7
	0.87	0	0	0	0		0.81
Trisomy 13	3	0	1	0	0	1	5
	0.44	0	1.48	0	0		0.58

Indiana

Birth Defects Counts and Rates 2003 - 2003

(Rates per 10,000 live births.)

	Race/Ethnicity						
Defect	Non-Hispanic White	Non-Hispanic Black	Hispanic	Asian or Pacific Islander	American Indian or Alaskan Native	Other / Unknown	Total
Trisomy 18	7	0	1	1	0	0	9
	1.02	0	1.48	22.73	0		1.04
Unspecified anomaly of heart	36	6	4	1	0	0	47
	5.24	6.49	5.91	22.73	0		5.44
Ventricular septal defect	225	19	20	2	1	11	278
	32.72	20.55	29.57	45.45	103.09		32.15
All Defects	2147	270	151	17	2	87	2674
	312.23	291.99	223.27	386.36	206.19		309.27
Total Live Births	68763	9247	6763	440	97		86462

The counts and rates of occurences of defects reflected in this report are based on the Indiana Birth Defects & Problems Registry Data. Only those conditions which have been confirmed or which have been determined to be highly probable by the Chart Audit Process are included in the data. This report is based on real time data and subject to change based on additions and corrections to the data.

Table 6:

Indiana

Trisomy Counts and Rates by Maternal Age 2003 - 2003

(Rates per 10,000 live births.)

	Age		
Defect	**<35**	**35 and >**	**Total(**)**
Down syndrome	51	31	85
	6.57	35.29	9.83
Trisomy 13	2	3	5
	0.26	3.42	0.58
Trisomy 18	5	4	9
	0.64	4.55	1.04
Total Live Births	**77,627**	**8,784**	**86,462**

The counts and rates of occurences of defects reflected in this report are based on the Indiana Birth Defects & Problems Registry Data. Only those conditions which have been confirmed or which have been determined to be highly probable by the Chart Audit Process are included in the data. This report is based on real time data and subject to change based on additions and corrections to the data.

Table 7: Indiana Confirmed and Probable Counts and Rates of the Targeted Conditions for 2003 Births by County (Rates per 1,000 live births)
Note: * Indicates < 5 in number occurred.

County Defect	Total Number Rate
ADAMS	
Atrial septal defect	**5** 0.58
All Defects	**18** 2.08
ALLEN	
Atrial septal defect	**69** 7.98
Cleft lip with and without cleft palate	**16** 1.85
Hypospadias and Epispadias	**12** 1.39
Microcephalus	**8** 0.93
Obstructive genitourinary defect	**12** 1.39
Patent ductus arteriosis	**25** 2.89
Pulmonary valve atresia and stenosis	**13** 1.50
Pyloric stenosis	**14** 1.62
Tetralogy of fallot	**5** 0.58
Unspecified Anomaly of heart	**7** 0.81
Ventricular septal defect	**22** 2.54
All Defects	**243** 28.10
BARTHOLOMEW	
All Defects	**22** 2.54
BENTON	
All Defects	*
BLACKFORD	
All Defects	**5** 0.58
BOONE	
Atrial septal defect	**11** 1.27
Obstructive genitourinary Defect	**5** 0.58
All Defects	**35** 4.05
BROWN	**5**
All Defects	0.58
CARROLL	
All Defects	*
CASS	
All Defects	**23** 2.66

County Defect	Total Number Rate
CLARK	
Atrial septal defect	**6** 0.69
All Defects	**21** 2.43
CLAY	
All Defects	**11** 1.27
CLINTON	
All Defects	**16** 1.85
CRAWFORD	
All Defects	*
DAVIESS	
All Defects	**16** 1.85
DEARBORN	
All Defects	*
DECATUR	
All Defects	**13** 1.50
DEKALB	
Atrial septal defect	**6** 0.69
Ventricular septal defect	**5** 0.58
All Defects	**23** 2.66
DELAWARE	
Atrial septal defect	**25** 2.89
Hypospadias and Epispadias	**7** 0.81
Obstructive genitourinary defect	**10** 1.16
Patent ductus arteriosis	**8** 0.93
Ventricular septal defect	**10** 1.16
All Defects	**80** 9.25
DUBOIS	
All Defects	**9** 1.04
ELKHART	
Atrial septal defect	**21** 2.43
Patent ductus arteriosis	**21** 2.43
Pulmonary valve atresia and stenosis	**5** 0.58
Pyloric stenosis	**12** 1.39

ELKHART con't.	
Spina bifida without anencephalus	**5** 0.58
Ventricular septal defect	**15** 1.73
All Defects	**116** 13.42
FAYETTE	
All Defects	*
FLOYD	
All Defects	**7** 0.81
FOUNTAIN	
All Defects	**12** 1.39
FRANKLIN	
All Defects	*
FULTON	
All Defects	**11** 1.27
GIBSON	
All Defects	*
GRANT	
Atrial septal defect	**5** 0.58
All Defects	**36** 4.16
GREENE	
All Defects	**11** 1.27
HAMILTON	
Atrial septal defect	**22** 2.54
Cleft lip with and without cleft palate	**7** 0.81
Down Syndrome	**5** 0.58
Hypospadias and Epispadias	**17** 1.97
Obstructive genitourinary defect	**27** 3.12
Patent ductus arteriosis	**14** 1.62
Pulmonary valve atresia and stenosis	**5** 0.58
Pyloric stenosis	**10** 1.16
Ventricular septal defect	**18** 2.08
All Defects	**164** 18.97
HANCOCK	
Atrial septal defect	**6** 0.69
Hypospadias and Epispadias	**7** 0.81
All Defects	**30** 3.47

HARRISON	
All Defects	*
HENDRICKS	
Patent ductus arteriosis	**5** 0.58
All Defects	**33** 3.82
HENRY	
All Defects	**15** 1.73
HOWARD	
Obstructive genitourinary defect	**5** 0.58
All Defects	**32** 3.70
HUNTINGTON	
Atrial septal defect	**19** 2.20
Hypospadias and Epispadias	**5** 0.58
All Defects	**36** 4.16
JACKSON	
All Defects	**16** 1.85
JASPER	
All Defects	**13** 1.50
JAY	
Atrial septal defect	**6** 0.69
All Defects	**14** 1.62
JEFFERSON	
All Defects	**8** 0.93
JENNINGS	
All Defects	**14** 1.62
JOHNSON	
Atrial septal defect	**11** 1.27
Cleft lip with and without cleft palate	**7** 0.81
Down Syndrome	**5** 0.58
Hypospadias and Epispadias	**6** 0.69
Pyloric stenosis	**5** 0.58
Ventricular septal defect	**5** 0.58
All Defects	**69** 7.98
KNOX	
All Defects	**12** 1.39
KOSCIUSKO	
Atrial septal defect	**16** 1.85
Hypospadias and Epispadias	**5** 0.58
All Defects	**38** 4.39

LAGRANGE	
All Defects	**27** 3.17
LAKE	
Cleft palate without cleft lip	**6** 0.69
Congenital hip dislocation	**5** 0.58
Down Syndrome	**5** 0.58
Hydrocephalus without Spina bifida	**7** 0.81
Hypospadias and Epispadias	**11** 1.27
Obstructive genitourinary defect	**11** 1.27
Pyloric stenosis	**8** 0.93
Renal agenesis/hypoplasia	**5** 0.58
Ventricular septal defect	**9** 1.04
All Defects	**100** 11.57
LAPORTE	
Atrial septal defect	**17** 1.97
Patent ductus arteriosis	**12** 1.39
Ventricular septal defect	**11** 1.27
All Defects	**76** 8.79
LAWRENCE	
All Defects	**21** 2.43
MADISON	
Atrial septal defect	**8** 0.93
Hypospadias and Epispadias	**6** 0.69
Ventricular septal defect	**7** 0.81
All Defects	**59** 6.82
MARION	
Atrial septal defect	**100** 11.57
Choanal atresia	**5** 0.58
Cleft lip with and without cleft palate	**15** 1.73
Cleft palate without cleft lip	**9** 1.04
Coarctation of aorta	**7** 0.81
Congenital hip dislocation	**5** 0.58
Diaphramatic hernia	**5** 0.58
Down Syndrome	**17** 1.97
Esophageal atresia / tracheoesophageal fistula	**6** 0.69

MARION con't	
Gastroschisis	**6** 0.69
Hydrocephalus without Spina Bifida	**17** 1.97
Hypoplastic left heart syndrome	**6** 0.69
Hypospadias and Epispadias	**56** 6.48
Microcephalus	**13** 1.50
Obstructive genitourinary defect	**44** 5.09
Patent ductus arteriosis	**56** 6.48
Pulmonary valve atresia and stenosis	**16** 1.85
Pyloric stenosis	**35** 4.05
Soina bifida without Anenceogakys	**5** 0.58
Tertrology of fallot	**6** 0.69
Transposition of great arteries	**9** 1.04
Unspecified Anomaly of heart	**7** 0.81
Ventricular septal defect	**47** 5.44
All Defects	**528** 61.07
MARSHALL	
All Defects	**6** 0.69
MIAMI	
All Defects	**15** 1.73
MONROE	
Atrial septal defect	**8** 0.93
Hypospadias and Epispadias	**5** 0.58
Patent ductus arteriosis	**6** 0.69
Ventricular septal defect	**6** 0.69
All Defects	**44** 5.09
MONTGOMERY	
All Defects	**12** 1.39
MORGAN	
Hypospadias and Epispadias	**5** 0.58
All Defects	**28** 3.24
NEWTON	
All Defects	*****
NOBLE	
All Defects	**20** 2.31

ORANGE	
Ventricular septal defect	**5** 0.58
All Defects	**15** 1.73
OWEN	
All Defects	*
PARKE	
All Defects	**6** 0.69
PERRY	
All Defects	**7** 0.81
PIKE	
All Defects	**6** 0.69
PORTER	
Pyloric stenosis	**5** 0.58
All Defects	**37** 4.28
POSEY	
All Defects	*
PULASKI	
All Defects	**9** 1.04
PUTNAM	
Atrial septal defect	**5** 058
All Defects	**22** 2.54
RANDOLPH	
All Defects	**8** 0.93
RIPLEY	
All Defects	**8** 0.93
RUSH	
All Defects	*
SCOTT	
All Defects	**10** 1.16
SHELBY	
Atrial septal defect	**5** 058
Ventricular septal defect	**6** 0.69
All Defects	**24** 2.78
SPENCER	
All Defects	*
ST. JOSEPH	
Atrial septal defect	**30** 3.47
Down Syndrome	**7** 0.81
Hydrocephalus without Spina bifida	**8** 0.93
Hypospadias and Epispadias	**6** 0.69

ST. JOSEPH con't.	
Patent ductus arteriosis	**39** 4.51
Ventricular septal defect	**13** 1.50
All Defects	**149** 17.23
STARKE	
All Defects	**11** 1.27
STEUBEN	
All Defects	**14** 1.62
SULLIVAN	
All Defects	*
TIPPECANOE	
Atrial septal defect	**9** 1.04
Ventricular septal defect	**7** 0.81
All Defects	**45** 5.20
TIPTON	
All Defects	**9** 1.04
VANDERBURGH	
Hypospadias and Epispadias	**5** 0.58
Ventricular septal defect	**6** 0.69
All Defects	**44** 5.09
VERMILLION	
All Defects	*
VIGO	
Atrial septal defect	**5** 058
Pyloric stenosis	**6** 0.69
All Defects	**38** 4.39
WABASH	
Atrial septal defect	**6** 0.69
All Defects	**20** 2.31
WARREN	
All Defects	*
WARRICK	
All Defects	**8** 0.93
WASHINGTON	
All Defects	*
WAYNE	
All Defects	**23** 2.66
WELLS	
Atrial septal defect	**6** 0.69
Ventricular septal defect	**7** 0.81

WELLS con't All Defects	**25** 2.89
WHITE All Defects	**13** 1.50
WHITLEY All Defects	**30** 3.47

TOTAL LIVE BIRTHS 86462